

## In This Issue



**Carol Fisch**  
Chronic  
Borreliosis  
Complex &  
Neuroendocrine  
System Disorders  
p. 2



**Barbara Loe Fisher**  
Vaccine Injury  
Compensation:  
A failed experi-  
ment in tort  
reform. p. 2



**Dawn Irons**  
Standing at the  
Gates, Looking  
at the Ruins  
p. 3



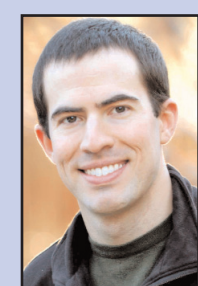
**Harriet Bishop**  
A Texas Style  
Riddle  
p.3



**Joan Vetter**  
How is Your  
Heart Vision:  
Eyes of Faith  
p. 4



**Lisa Copen**  
How to Plan a  
Women's  
Retreat so the  
Chronically Ill  
Will Attend  
p. 4



**Bryan Rosner**  
Attention Lyme  
Disease  
Physicians:  
Should You Write  
a Book?  
p. 6



**Andrea Candee**  
Should I take the  
Flu Vaccine?  
p. 6



**Dr. Virginia Sherr, M.D.**  
The Pillaging of  
Personalities:  
Our Lost Kids  
are Being  
Highjacked by  
Spirochetes  
p. 12

## Lyme Community Loses Hero & Friend Leslie Wermers's Battle Ends

by *Andy Abrahams Wilson*  
Producer/Director  
**UNDER OUR SKIN**

The Lyme community has lost an important hero and friend. Leslie Wermers, 41, died from heart failure in her sleep on November 2nd. It's hard to imagine Leslie's heart stopping, because for anyone who knew her, she was all heart. A dear friend to so many and a tireless worker on behalf of the Minnesota and national Lyme communities, Leslie gave everything she had to help others who were sick. And everything she had was an abundant reserve of love and support—even as her own health waned.

The first time I heard from Leslie was in an email several years ago during production of **UNDER OUR SKIN**. She said that watching the film trailer changed her life: "You see, Andy, I had no will to live. I was so sick, with no answers and just wanted it to end. That was until I saw the trailer. You have given me so much joy. Your documentary saved my life."

Since then, Leslie became our greatest film fan and an undying activist. I finally met her at the Iowa Lyme memorial which we covered for our film. Though she herself drove more than four hours to be there, she gave our crew a hero's welcome. What she told me during an on-camera interview there was humbling and prophetic.

"I have lost my life to this disease, but coming here will help me get it back. The strength you get from others—and by God we're getting more and more powerful. I will get my life back. And I will help others get their lives back. If I

die tomorrow and I save one life, I'll die happy."

Months later, Leslie and her sister Tracie (who also has Lyme and worked with Leslie on behalf of Lyme sufferers) sent us a picture of their version of the film's widely-used image of Mandy in the pool.

Leslie wrote, "Tracie and I thought that this photo represents our passion to continue to help you finish this project, that will save so many lives."

Beyond her mission of service, Leslie's sense of humor and gusto were legendary. Over the next few years hers was a familiar voice in our office—calling regularly to tell us how much she appreciated our work, how we were her "angels," and how much she "loved" us. But her love didn't stop here. It was extended to so many people nationwide who were sick and struggling in solitude with the disease. Leslie and Tracie founded the support group Minnesota Lyme fighters Advocacy. Suffering from Lyme induced insomnia, she had late-night conversations with people across the country—many of whom she had never met—offering them words of encouragement, hope and affection. It is a testament to her profound affect on so many and the deep emptiness she leaves that so many have been moved by her passing, never having even met her.

Leslie's death leaves a deep hole in my heart and in so many others. Her indomitable spirit and passion for life were equaled only by her anger at the injustices wrought by Lyme ignorance and her dedication to help heal. May this be the lesson—Leslie's legacy—for all of us. *pha*



**Above:** Leslie Wermers, well-loved Lyme patient and advocate, passed away November 2, 2008. **Below:** Leslie & her sister Tracie Schissel do a mock version of Under Our Skin's famous pool scene.



## A Tribute to Leslie... by Bryan Rosner

Leslie (along with her sister Tracie) is a hero who founded the Minnesota Lyme Fighters Advocacy Group. After Leslie passed away I felt compelled to share some information about her amazing life.

This loss is so tragic, it has been keeping me up at night. I met Leslie just days before her death at the 2008 ILADS conference. Her spirit touched me even then.

Leslie and Tracie

(Leslie's sister) are awesome. They are the brightest and truest spirits in the Lyme community that I have ever met. When I first met Tracie and Leslie, I kept waiting for their first-impression angelic qualities to wear off into real life relationship that comes when you actually "know someone well." But the better I got to know them, the more conversations I had, and the more their true character was revealed...

the clearer it became that no - this was not just a first impression and no, this was not just a "show" - this was who they truly were, out there on the front lines, staying up late to help people, spending hours on the phone with desperate patients. Their behavior should be a model for all of us.

In my line of work I get phone calls from way too many people but whenever Leslie would call me, my face would

light up and it would be as if time would stand still. I could just tell that there were no pretenses, just caring affection and the desire to help.

May the Lord Jesus Christ bless and keep you, Leslie, and we will never forget your kindness, passion and spirit which reached across thousands of miles as if it were next door. *pha*

[www.truthaboutlymedisease.com](http://www.truthaboutlymedisease.com)

Everybody has a story... we want to hear yours.



# Chronic Borreliosis Complex and Neuroendocrine System Disorders



by Carol Fisch

Most medical professionals, when speaking of Lyme disease, are typically referring to an outdated and over-simplified version of the disease that was once taught and believed that the main causative agent being dealt with was the borrelia spirochete. We now know there are many agents involved. Borreliosis Complex for Lyme disease is a better term than just Lyme disease. We now know there are many agents involved and much neuroendocrine involvement due to not only Borrelia, but viral activity and damage to the Methylation cycle (KREBS CYCLE). It is so good to see the two groups learning from one another. Initially the group of Lyme researchers was looking at only Borrelia the causative agent for Lyme disease but as time went on they discovered many other agents. The CFIDS doctors were looking at damage to the Methylation cycle, Diastolic Heart Dysfunction and so much more in their research endeavors. It appears one group was looking for the AGENTS and the other was looking for the DAMAGE. It is so gratifying to me not only a researcher but a victim of these issues to see the two groups coming together. There are researchers in the Lyme community and in the

CFS/Fibro Community who are looking at all the above and below issues. I prefer the name Neuroendocrine System disorders to CFS as this is what happens to all of the victims regardless of the diagnosis: Much needed change is slow in all research but the two groups are coming together and sharing their findings. We will all benefit from this cooperation. Not all patients with a CFS diagnosis have Borrelia (Lyme) Complex but as you can see from below, many of us share some of the causes and some of the damage. Some on the Lyme disease side believed the organisms to be the only problem. Some of the CFS/Fibro side felt -and many still do- that if the damage is corrected, the infections may go away on their own. We have a long way to go but in working together hopefully we can come up with answers that help all of us to live healthier and more productive lives.

A simple explanation of Lyme disease is not possible, as Lyme disease is not a simple disease. It is not just an infection with Borrelia burgdorferi, the causative agent of Lyme disease. We are dealing with an illness complicated by multiple infectious agents, many of them being immune suppressive. The immune system has difficulty in detecting the organisms due to multiple factors, pleomorphism (Changing its morphology in order to survive is one of its best tricks). From the moment it gets into the body, it has the ability to lock itself into our own DNA proteins. When hit by anything that might threaten, it can go into Cell Wall Deficient (CWD) stages or into the Cyst stage, a very protective stage. An activated immune system, where the body is trying to find an enemy and can't, leads to reactivation of Herpes Virus 1 through 6

and auto-immune issues. Many patients given a diagnosis of CFIDS, Fibromyalgia, Gulf War Illness or Neuroborreliosis Complex (Lyme disease) are dealing with a very complex organism that causes multiple damage to the host. It is indeed a very complex organism within itself. Borrelia burgdorferi is one of the players in Neuroborreolosis Complex. It has 132 lipoproteins, genes and more genetic material than any other bacteria. Ninety percent of the genes are not related to any other bacteria, perhaps making it the most complex organism known. Syphilis, by comparison, has 22 lipoproteins in its genetic make-up, making it look like a wimpy cousin of Borrelia burgdorferi in comparison. Some of the other NeuroSystemic infections, Chronic Fatigue, Fibromyalgia, Systemic Lupus Erythematosus, Schlerdoma, Pneumonia, Bronchitis, Inflammatory Bowel Disease, Kikuchis Johnson syndrome, MS, ALS, and Parkinsons and most likely many more have been found to harbor many of these infections that are very capable of being stealth pathogens.

- Mycoplasma fermentans (Incognitos strain and various other strains.
- Human Herpes Virus-6a (HHV-6a) a very immune-suppressive virus found in Neuroendocrine Disorder, Lyme, HIV, CFS as well as others.
- Chlamydia pneumonia (Chronic Chlamydia pneumonia). Charles Stratton, M.D. out of Vanderbilt University has come up with a protocol to deal with this very complex pleomorphic infection that is present in so many patients with the various diagnoses. His protocol

- can be found at [www.cpnhelp.org](http://www.cpnhelp.org)
- Other pathogens found:**
- Mycoplasma pneumonia
  - Mycoplasma hominis
  - Ureaplasma urealyticum
  - Mycoplasma penetrans
  - Borrelia burgdorferi (Chronic Late Stage Lyme) and may also trigger Fibromyalgia
  - Brucellosis (Chronic Brucellosis)
- Rickettsia Diseases:**
- Rickettesia ricketessi
  - Coxiella burnetii (Qfever,"Post-Q-Fever fatigue Syndrome")
  - Staphylococcus and Streptococcus
- Viruses:**
- Epstein- Barr Virus (EBV) reactivation
  - Cytomegalovirus (CMV) reactivation
  - Coxackie B Virus (1-6) chronic Coxackie infection which may cause/trigger CFS, Myalgias and other diseases).
  - Parvovirus B-19 (Chronic Parvovirus infection "may cause/trigger Fibromyalgia/ CFS, arthralgia, arthritis. Hepatitis C (Chronic Hepatitis C" may cause/trigger Post-Polio Syndrome non-Paralytic Polio," Chronic inflammatory muscle disease, Fibromyalgia/ CFS).

A simple explanation does not give the complexities of the many organisms or the diseases and complications they cause. Lita Mattman, Ph.D. and Alan Macdonald, M.D., Ph.D. are studying the pleomorphic stages of many organisms. I studied under Dr. Mattman... The studies and live photos show the organism's ability to evade detection by anti-microbials, and the patient's own

immune system; again, leading to auto-immune issues, among other things, in many of us. Physicians on both coasts, California and Connecticut, have found many of these same organisms in blood-sucking insects. There may be others we are not aware of as yet. Eva Sapi , Ph.D of the University of New Haven Dept. of Biology and Environmental Science, found many of the pathogens in ticks on the east coast that were found on the west coast. The bottom line is that many of us are dealing with an immune system that has been driven into Humeral Immunity (over-drive) and stays activated, due to the inability to find and destroy the enemy within and the neuroendocrine damage that results. Again, as both groups work together, sharing information and research, we will hope for a better future for all who suffer from Neuroendocrine Disorders. *pha*

## About Carol Fisch:

Carol Fisch is an Adjunct Professor Emeritus of Laboratory Science, Researcher, Medical Laboratory Advisor for Tick-Born illness testing and education to others in regards to Tick-Born illness. Carol Fisch is well-versed in Microbiology, Immunology and Parasitology with an excellent understanding of Cell Wall Deficient Organisms (CWD). She is a Stealth Pathogens Researcher, teacher, advocate and activist for those suffering from stealth pathogens and Neuroendocrine disorders.

# Vaccine Injury Compensation: A Failed Experiment in Tort Reform?



by Barbara Loe Fisher

On Nov. 14, 1986, President Ronald Reagan signed the National Childhood Vaccine Injury Act of 1986 into law, instituting first-time vaccine safety reforms in the U.S. vaccination system and creating the first no-fault federal vaccine injury compensation program alternative to a lawsuit against vaccine manufacturers and pediatricians. Twenty-two years later, on Nov. 18, 2008, I made a statement to the Advisory Commission on Childhood Vaccines (ACCV)

and questioned whether the compensation program is fatally flawed and so broken that it should be repealed. Many parents are wondering whether it would be better to return to civil court without restrictions to sue vaccine manufacturers and doctors for injuries and deaths their children suffered after receiving federally recommended vaccines. During its two-decade history, two out of three individuals applying for federal vaccine injury compensation have been turned away empty-handed even though to date \$1.8B has been awarded to more than 2,200 plaintiff's out of some 12,000 who have applied. Today, nearly 5,000 vaccine injury claims are sitting in limbo because they represent children, who suffered brain and immune system dysfunction after vaccination but have been diagnosed with regressive autism, which is not recognized by the program as a compensable event. There is \$2.7B sitting in the Trust Fund which could have been awarded to vaccine victims.

At the time of the law's creation in 1986, Congress said they were committed to setting up a fair, expedited, non-adversarial, less traumatic, less expensive no-fault compensation mechanism alternative to civil litigation. But Congress also acknowledged that any legislation providing liability protection must also be equally committed to preventing vaccine harm. The Act contains strong safety provisions, including first-time mandates for doctors to record and report serious health problems, hospitalizations, injuries and deaths after vaccination and give parents written benefit and risk information before a child is vaccinated. But few of the safety provisions have been enforced and, as I testified in Congress in 1999 and again at the Nov. 18 ACCV meeting, there has been a betrayal of the promise that was made to parents about how the compensation program would be implemented. Obtaining compensation has become a highly adversarial, time-consuming, traumatic and

expensive process for families of vaccine injured children and far too many vaccine victims have been denied compensation while vaccine makers and doctors have enjoyed liability protection and dozens of doses of nine new vaccines have been added to the childhood vaccine schedule. I pointed out that federal court judges are beginning to look back at the legislative history of the Act, which so clearly affirms the intent of Congress when creating it. In recent court decisions, judges have agreed with parents and their attorneys that the compensation program has become far too difficult for plaintiffs. A recent state Supreme Court ruling also reiterated that Congress never intended to shield vaccine manufacturers from ALL liability for vaccine injuries and deaths when it could be demonstrated that a safer product could have been marketed. In a Supreme Court of Georgia ruling on October 6, 2008 in American Home Products v. Ferrari, the justices

unanimously held that the National Childhood Vaccine Injury Act does not give a vaccine manufacturer blanket immunity from vaccine injury lawsuits if it can be proven that the company could have made a safer vaccine. Georgia Supreme Court Justice George Carley wrote that the 1986 law and "the congressional intent behind it shows that the Vaccine Act does not pre-empt all design defect claims." He added that Congress did not "use language which indicates that use of the compensation system is mandatory" but only "an appealing alternative" to the courts. Justice Carley wrote that there is no evidence that "FDA approval alone renders a vaccine unavoidably safe" and said "We hesitate to hold that a manufacturer is excused from making changes it knows will improve its product merely because an older, more dangerous version received FDA approval," adding that to do so would have "the perverse effect" of granting complete *“Vaccine Injury” cont’d pg 10*



Public Health Alert

The PHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the United States. We have joined our forces with local and nationwide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gehrig's Disease (ALS), Lupus, Chronic Fatigue, Fibromyalgia, Heart Disease, Cancer and various other illnesses of unknown origins. PHA seeks to bring information and awareness about these illnesses to the public's attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritual-ly and medically.

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Standing at the Gates,  
Looking at the Ruins



by Dawn Irons

I recently received a very precious, precious gift. It is not one that I can display on a shelf, or hang in a place of honor in my home-it was a far more treasured a gift than that... it was a healing of a wounded spirit.  
  
I attended college at the University of Mary Hardin-Baylor in Belton, Texas (UMHB). The campus has an extremely rich historical heritage. I remember soaking in all the UMHB Crusader history with great pride. I knew from the day I stepped foot on the campus that I would be a Crusader forever! I would almost believe that if you cut me I would bleed purple and gold!  
  
One of my favorite places on the campus was the Luther Memorial which we simply called "the ruins". Eons ago there was a building called Luther Hall that had caught fire and all that was left was the bell tower and the multiple archway entrances. These "ruins" were preserved and made into a memorial that has become a campus icon for generations. The Easter pageant is held at the ruins. Weddings have been held at the ruins. When you think UMHB-you think "the ruins!"  
  
The ruins signify a once-tragic event in the life of the university-a gaping wound in the history and the heart of the UMHB heritage..... And yet, it is beautiful.



*The Luther Memorial "ruins" on the campus of the University of Mary Hardin-Baylor in Belton, Texas.*

The precious gift I received recently came in the form of an invitation. I was invited to come back to UMHB and speak to their school of Journalism. They wanted to hear from an Alumnus who had once been editor of the UMHB school newspaper, The Bells, and had gone on to continue work in the newspaper and journalism profession.  
  
As I arrived on campus, one of the first things I did was to seek out the ruins! I love the ruins! Oddly though, another one of the campus iconic landmarks had been moved and now sort of "framed" the ruins. It made the most beautiful photo for any UMHB fan! So I was standing at the gates looking at the ruins and I was struck with the irony of what had brought me to this place.  
  
I thought it was rather ironic that my field of study while at the university was actually in Social Work, not journalism-though journalism had been my first choice. At that time, the school did not have a journalism department. Social Work just seemed fitting. There has always been an advocate inside of me-it is in the fabric of

my being. I would just go about my goals through the avenue of the Social Work department and spend my time volunteering on the school's newspaper and yearbook until such a time came when the editor's position was available and I was hired for the job. This satisfied that desire for journalism in my life, even though I knew a journalism degree would not be at the end of the journey.  
  
So there I was standing at the gates of UMHB looking on the ruins. The thoughts of being invited to speak to the school's journalism department flooded me with emotions. I was so excited that the dream I had once wanted was now available to future students, and there was a sense of Crusader pride that just welled up inside me. But the irony of how I actually ended up in the field of journalism kept pervading my thoughts. There is just no other word but irony that describes the situation...and it was the very reason UMHB invited me back to speak to this new generation of journalists: my newspaper publication The Public Health Alert and, by association, Lyme disease.

Again, staring at the ruins of UMHB, I realized it was the ruins of my own life that brought me back to this place. It was the devastation and destruction of Lyme disease and realizing what others were going through-and then with the social work training, the advocate inside did all I could do, under the circumstances. I took the journalism skills I had learned in junior high and high school, and fine tuned while being the editor of the UMHB Bells, and arose from the ashes, much like a phoenix, and created the PHA to help Lyme patients and their medical providers have a platform to share information without outside interference.  
  
Much like UMHB's ruins signified a tragedy of the past, I am finding that the ruins of what Lyme has done in my life, though it has had it's tragic moments, is also becoming the very thing that people are now being drawn to and are finding beauty in -much like the Luther Memorial at UMHB.  
  
I find when I tell my Lyme story, when I reflect on all that Lyme has done in my life-  
*"The Ruins" ... cont'd pg 13*

A Texas Style Riddle

Perks from the Pistol Packin' Texas Grandma



by Harriet L. Bishop,  
President TxLDA

Like riddles? Here's one for ya'll!  
  
What do these people have in common?  
  
Two veterinarians, a feed store owner, a rancher/restauranteur, the owner of a

health food store, a recreation center director, a chiropractor, a youth camp director, a college disability services professional, and two newly diagnosed Lyme patients with their supportive family members...  
  
Give up?  
  
All sat spellbound in the crowd as Andy Wilson's remarkable film "Under Our Skin" weaved its tale of intrigue at Ed's Old Windmill, Canyon Lake, Texas, in the heart of the beautiful Hill Country on Wednesday, November 12, 2008.  
  
They were welcomed by the Texas Lyme Disease Association's awesome 15 foot banner proclaiming "GIVE LYME THE BOOT!" which was nailed across the old wooden front porch, picturing a Lone Star tick being boot-kicked

across Texas.  
  
Questions flew freely after the viewing, and a lively discussion followed as folks shared their Lyme experiences, with helpful tips for those just entering this new and challenging phase of their lives.  
  
As the deer population explodes unchecked in these cedar-covered hills, the infected ticks multiply too. Deer graze freely on front lawns and in back yards among children's play areas. Local rheumatologists scratch their heads in wonder, diagnosing more and more cases of "fibromyalgia" among young mothers.  
  
Wouldn't you think that's a riddle they could figure out?  
  
And what about the children? Lyme, CT, all over again?  
  
*pha*

**Texas Lyme Disease Association**



*Giving Lyme the boot!*

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How is Your Heart Vision: Eyes of Faith



by Joan Vetter

At first I just attributed it to an overactive imagination. I had closed my eyes to pray on Capitol Hill, along with 2000

other women from Aglow, when I "saw" a person in a t-shirt with a big pair of glasses across their chest. Then this image dogged my mind - it would pop back in at will. Finally I realized God just might be involved in this when I heard the words we were singing...."open the eyes of my heart, Lord - I want to see you." Also, the scripture in Ephesians 1: 17 speaks of our understanding having eyes - "the eyes of your understanding being enlightened".

When someone has lost their physical sight, we can describe a scene such as a log cabin in the woods by saying it

is surrounded by pine trees, the cabin has a long porch with rocking chairs, and there is smoke pouring out the chimney. Thus a picture is formed in their mind. That is where the term "mind's eye" comes from. However if someone was born blind and we described the cabin they would not have a template to bring the description alive.

That is the same in our Christian faith. We first must have our eyes opened to know that Jesus Christ is who He claims to be, and from then on we grow increasingly aware of the picture scripture paints of Him. And it is through our

spirit the revelation will come. In 2 Corinthians 4:16-19 (Message Bible) we are encouraged with these words: "So we're not giving up. How could we! Even though on the outside it often looks like things are falling apart on us, on the inside, where God is making new life, not a day goes by without his unfolding grace. These hard times are small potatoes compared to the coming good times, the lavish celebration prepared for us. There's far more here than meets the eye. The things we see now are here today, gone tomorrow. But the things we can't see now will last forever."

Have you ever been talking to someone and suddenly a light went on, and you felt like they understood what you were trying to say. They might have said, "yes, I see". Well, obviously there wasn't anything in front of their eyes that caused them to "see". It was in their heart and mind. That's what it means when the Bible says "with the heart man believes unto righteousness". The eyes of our heart are opened to see God.

How is your heart vision? Is it 20-20, or does it need some correction? *pha*

How to Plan a Women's Retreat  
So Those with Chronic Illnesses Will Attend



by Lisa Copen

Who are the women who are attending your church retreats? Did you know that nearly 1 in 2 people in the USA have a chronic illness and practically 96% of the illnesses are invisible? Most of these women suffer silently; many live with depression, isolation, and feel very alone. But you will also discover many women who live with illness possess great wisdom beyond their years; they will make a difference in the lives of others who are attending your retreat, perhaps even beyond the retreat speaker. But are they even attending the retreat?

Rest Ministries, the largest Christian organization that serves the chronically ill, took a survey about attending retreats. Out of the twenty respondents, seventeen participate less since they have a chronic illness. When asked why, the responses were as follows: Three explained,

"Accessibility issues (It's difficult to get to and from buildings at the retreat)"; 6 people responded, "The pain factor. It's just too draining"; 4 shared, "The unpredictable health issues"; and 10 said, "A combination of the above."

**So, how could you encourage women with chronic illness to get involved in your church retreat?**

When planning the retreat ask a lot of questions about the retreat center and promote that you have this information before people register.

How steep are the hills? Are ride-in carts available? How far are the rooms from the main meeting center? Is electricity available in the rooms? Are there only bunk beds? Can someone have a private room? Are there chairs besides the metal folding chairs? Elevators?

One woman shares, "I stopped going a year or so ago because the retreat planner does not tell you what is expected, or about walking, stairs, etc. They need to be more honest."

Those who attend retreats look for locations that are held at retreat center without a lot of walking, and preferably flat ground. Hotels or a large home are nice too. While you may think fifty yards is a "short distance," fifty steps may be one's limit. Provide actual distances on your flyer, not just "rooms are a short walking distance."

**Understand that women desire to go on retreats and socialize with others, but they must feel that the retreat planner understands that they will be on their own schedule.**

Margaret lives with a malignant brain tumor and uterine cancer. She says, "I don't attend retreats because people don't want to understand or accept that sometimes I have to retreat from the 'retreat.' I may have to go back to my room to rest. Others decide that I'm escaping from my problems. They demand that I participate in whatever is happening. I'm not wishing to be anti-social and I will participate when God enables me to do so; but at the same time, when God tells me to rest, I must rest despite what the retreat 'timetable' states."

One way a retreat director can help rectify this is by distributing the retreat's event schedule a week or so before the event, even if it's just posted on the church's web site.

**When planning ice-breakers or fun games, make sure there is something comfortable those with limited physical abilities can do if they choose.**

If people don't want to participate in the relay race where everyone dresses up in costumes, allow them to do their own thing. Debbie, who has chronic fatigue syndrome says, "Unfortunately, I have yet to find a retreat director who

understands that I am not able to participate, not because I'm uncooperative, shy, or antisocial, but simply because I cannot physically do so; the result is that I do not attend church retreats."

**Don't gasp at all they pack.**

All women have necessities they pack to make their weekend more comfortable. For the chronically ill, these typically include: their own bedding, chair cushions, pillows, snacks, pain patches, eye shades to sleep, or a flashlight and book to read in case she is awake all night. They may bring bottled water, the biggest collection of medication you've ever seen (don't comment), and perhaps even a service dog (which she should ask you about before the event.)

**Remember that she knows her body better than you do, and she is trying to plan for the best experience.**

She realizes that riding a bus to the retreat center may throw her back out the whole weekend, so if she can go in a car with a staff member, that modification is very beneficial. If she wears ear plugs or listens to music, don't take it personally. She may need to save her strength to socialize that evening. If she is diabetic, she may be eating small meals or snacks throughout the day. Don't comment, "Oh, we're going to be eating in thirty minutes, so why don't you just

wait."


**Acknowledge that she's not a prima donna; take her requests seriously.**

She isn't asking for the bottom bunk and bringing her bedding because she is the *Princess and the Pea*. She may have some required needs. For example, electricity is a medical requirement, not a wish, for women who use a CPAP machine for sleep apnea (2 women out of our responses of 20 use one). Refrigeration of medications may also be necessary, so don't tell her to just find an ice pack for her room. Her medication could be ruined so she may need access to a staff member who can get into the kitchen. Sheryl, who has chronic myofascial pain reminds us, "Make sure there are always chairs available for those who can't stand more than a couple of minutes." Don't assume just because you don't see a cane, means she is fine.

**Realize that she may not want others to know about her illness.**

Marjorie says, "When an explanation is given in confidence, don't react so that everyone present knows that I have a problem," and Anjuli, who has congenital myopathy (a form of Muscular Dystrophy) agrees. "Don't single me out!"

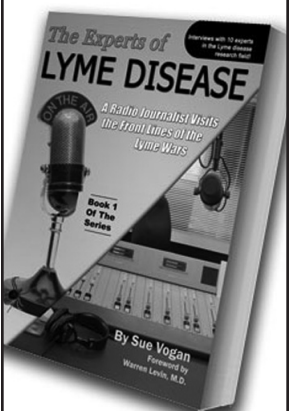
**Make scholarships available.** Financial constraints often hold *"Women's Retreat" ...cont'd 14*



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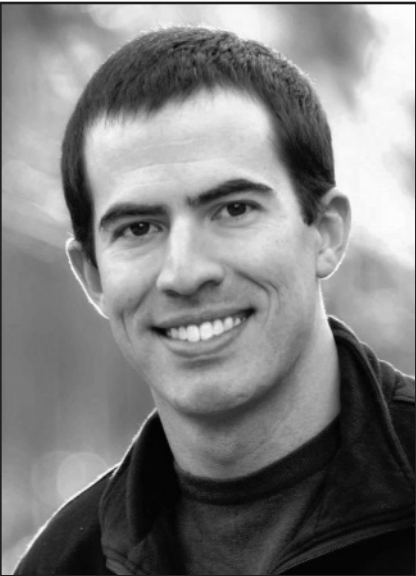
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# Attention Lyme Disease Physicians: Should You Write a Book?



by Bryan Rosner

(If you are a patient, advocate, or caretaker and you are considering writing a book, this article will probably be helpful to you too).

Physicians who specialize in Lyme disease are clearly the best candidates to write books on Lyme disease. The most common reasons that these physicians do not write books (from my discussions with several of them) are the following:

1. “I’m too busy and don’t have time.”
2. “Lyme disease doc-

tors are already being persecuted, and having a published book would be like painting a bulls-eye on my back for all the regulatory agencies to see.”

3. “The treatments I currently use for my patients still require additional testing and trials.”

If you are reading this and you are a physician, my purpose in penning this article is not to convince you to write a book. Instead, I will simply provide what I believe to be reasonable responses to the above questions based on my experience and research. Disclaimer: Your mileage may vary; this discussion is for informational purposes only.

Let’s begin with the first point. Yes, you are too busy; you are probably too busy to even spend enough time with your family and friends. Perhaps you are worked into the ground and wish you could cut 20 hours per week out of your schedule. Consider this, though: When you retire or die, how is the next generation of doctors going to know all that you have learned? Who will carry the torch? In my opinion, what you leave behind in terms of replicable wisdom is just as

important as the clinical help you’ve provided during your career. A book is a good tool for passing on knowledge to the next generation of physicians.

Regarding point number two: yes, this is true, Lyme disease physicians are currently being persecuted and you may be better off not going public. Nevertheless, a few recent developments have worked in your favor if you desire to write a book:

1. Lyme disease is rapidly gaining national attention which may mean that, as true science prevails and chronic Lyme disease is seen as a real condition, Lyme physicians may soon be vindicated instead of persecuted.
2. Writing a book is covered by different laws than treating patients. Writing a book falls under first amendment protection as freedom of speech and freedom of the press, so technically, you are not held to the same scrutiny that governs the clinical environment. I have combed the laws on this for hours and it is not completely clear to me how much you can get away with in this regard. It appears that most books are safe. But don’t take

my word for it – talk to a lawyer.

3. Thanks to Ken Singleton, M.D., you will not be the first physician to write a book on Lyme disease should you choose to follow through with a book. Dr. Singleton’s excellent book, *The Lyme Disease Solution*, was published on February 1, 2008. So, Dr. Singleton is essentially a “test case,” and we can all watch and see how it plays out. I would like to thank Dr. Singleton for his bravery and immense contribution to the Lyme disease community. His book is a tremendous asset to us all. James Schaller, M.D., is another brave physician pioneer who has “gone public.”

Moving on to point number three: Indeed, your clinical and research experience is not 100% complete and accurate; if it were, you would have found a cure for Lyme disease already. So, the real question is not whether you have all the answers for your book, but instead whether or not the information you’ve collected over your medical career is worth sharing. The answer is almost certainly yes. If you have had success treating Lyme

disease (even without a 100% cure rate), other physicians and patients can benefit from that knowledge. If you have not had success, benefit can also be gleaned from your mistakes. Most likely it is a combination of the two (success and failure), and your knowledge will provide a road map for those to come.

Should you write a book? Making the decision to do so is very personal. The project takes hundreds of hours. You need your family’s support, and if you are going to take time off work so as not to increase your workload, you may lose income. Only you and your loved ones can make the decision (and maybe your lawyer can help).

I am the author of four Lyme disease books and I also own BioMed Publishing Group and have been publishing Lyme-related literature full time since 2004. If you would like to speak more about this topic, call me at (530) 541-7200. Or, visit my website at [www.LymeBook.com](http://www.LymeBook.com). Submit a book proposal at [www.LymeBook.com/submit-book-proposal](http://www.LymeBook.com/submit-book-proposal).

pha

## Should I Take the Flu Vaccine?

share with you what I have learned so you can make your own educated decisions.

### Is it the 'flu'?

What we often experience in winter as coughs, head congestion and fever, may or may not be the flu. Oftentimes it is an upper respiratory infection (URI) but not influenza. Usually high fever, intense body aches, and malaise accompany influenza. Flu vaccines are not designed to address URIs. Pneumonias can be serious, but again, they are not influenza. Influenza is a virus and viruses are not affected by antibiotics. Often antibiotics are given when one has the flu to prevent bacterial complications, especially in those with compromised lung function (asthmatics, for example, and those prone to pneumonia).

### Tarnished Studies

While previous studies thought flu vaccines cut the risk of dying in the elderly by 50%, the reality is more like 5-10%. Research shows that while triple the people received annual flu shots between 1980-2001, there was no corresponding drop in the death rate.

Frequently resourced studies indicating reduced hospitalizations and pneumonia less likely due to flu vaccines have been found to be flawed. For people over the age of 65 living in nursing homes, the vaccine was often protective against complications of the flu, such as pneumonia. However, for those over 65 living on their own, the protective effects were negligible.

Children under the age of 2 receive no more benefit from the vaccine than a placebo. I consider this recommen-

dation questionable, since it is not based upon years of study in infants and toddlers. There are no long-term studies of the safety of flu vaccines over time.

### The Educated Guess

Healthy young adults received benefit when the flu vaccine exactly matched current strains. But because the flu vaccines are made well in advance of the winter season, only educated guesses can be made as to what strains will be around and often it turns out that important strains are missed and all those vaccinated received little or no protection for that season.

There are hundreds of strains of influenza (the viruses are clever at mutating) but only three strains of influenza are contained in the flu vaccine each year. Oh, well? This is science? Overall, flu shots in healthy young adults lowered the number of work days missed by less than a day.

A 2008 study reported in the prestigious British medical journal, The Lancet, sheds new light. The study called into question much of the statistical evidence for the vaccine's benefits, finding that over the course of three flu seasons, flu shots did not reduce occurrences of pneumonia in people aged 65-94. In fact, incidents were higher in those vaccinated. They concluded that either influenza is not a primary cause of pneumonia or the vaccine is ineffective.

### If you're healthy...get a flu shot?

As for the phenomenon linking lowered chance of getting pneumonia after having had a flu shot, after thorough analysis the researchers concluded that those who were

healthier and more conscientious about staying well were more likely to get an annual flu vaccine (and, therefore, due to their better levels of health, less likely to develop pneumonia anyway). Those who are in frail health (diminished lung function, inability to take care of themselves) and unable to get to the doctor's office for the flu shot, may well be more susceptible to begin with. The amount and type of medications taken may also predispose one to influenza by compromising the immune system.

### The Aging Immune System

Vaccines use the immune system to recognize and attack invading pathogens. Studies show that the elderly need four times the amount of antigens given in a standard dose of the flu vaccine to achieve immune response, as given to healthy adults under the age of 40. As we age, our immune function diminishes compared with children and younger adults.

The very system the vaccine needs to properly function is already compromised in the elderly. Study of previous data reveals that statistics for healthy vs frail subjects and flu vaccine effectiveness were not measured and most likely skewed the results made popular to the public. The study supports the growing number of immunologists and epidemiologists who say the vaccine doesn't work so well in people over 70, the group that has the highest number of deaths from flu.

What is for certain is that flu vaccines have only been put through one large study comparing them to placebo, the gold standard for medical evidence. If that base of evidence was not valid, then we have been following inaccurate advice.

### Safe for my family?

You may stand in the grocery aisle spending lots of time reading the long list of ingredients on cereal boxes and frozen meals. How much time have you spent reading the list of ingredients in the flu vaccines? Has your medical team offered the ingredients for your review? Or do we accept everything we are told on blind faith? What we often forget is that everything we are told by our medical support is based upon what they are told to be true. What if they have been unknowingly using inaccurate studies upon which to base their opinions?

According to the Cochrane Collaboration, a well-respected non-profit organization that reviews medical therapies, the safety of inactivated vaccines in children under the age of 2 was studied only once, 35 years ago, with just 35 children and found to be no better than a placebo.

They further found that healthy people under the age of 65 did not receive benefits from the vaccination such as decreased hospital stay, less time off work, or fewer deaths from influenza and its complications.

### Knowledge Makes For an Informed Decision

Flu vaccines contain:

- ❖ inactivated (killed) influenza viruses prepared from the embryonic fluid of the chick eggs in which they are grown (people with egg allergy must avoid flu vaccinations)

- ❖ antibiotics such as Neomycin and Streptomycin (be aware of allergies to antibiotics)

“Flu vaccine” ...cont’d pg 14



# ILADS President Calls for More Comprehensive Dialogue To Prevent Chronic Lyme Disease

## Patients Deserve To Be Fully Informed About Treatment Options

by *www.ilads.org*

Bethesda, MD—Oct 22, 2008 – During his closing remarks at the 2008 Scientific Meeting hosted by the International Lyme and Associated Diseases Society [www.ilads.org](http://www.ilads.org), Dr. Daniel Cameron, ILADS president, stressed the need for more comprehensive dialogue between physicians and researchers regarding the prevention of chronic Lyme disease. Almost 300 physicians, researchers and other medical professionals attended the two-day ILADS conference designed to foster collaboration and dialogue between Lyme disease researchers and those who care and advocate for Lyme disease

patients in a variety of settings. Held in San Francisco, the 2008 event drew the most geographically diverse group of professionals ever.

“Recommending appropriate outdoor dress, environmental control and short term doses of antibiotics are not enough to prevent chronic Lyme disease,” said Cameron. “Physicians need to adopt a broader perspective in order to help patients avoid years of chronic, debilitating illness. Patients need to be informed of their treatment options.”

Reports of chronic Lyme disease continue despite several secondary preventative strategies promoted by the Infectious Disease Society of America (IDSA) and the Center

for Disease Control (CDC) including narrow diagnostic criteria and short term (30 days or less) antibiotic treatment schedules. The most often referenced Lyme disease studies demonstrate patients can remain sick many years after treatment.

Two schools of thought have emerged regarding the diagnosis and treatment of Lyme disease. The Infectious Disease Society of America (IDSA) clinical practice guidelines (CPG) conclude there is no evidence of chronic Lyme disease and characterize post-treatment symptoms such as chronic fatigue, migraine headaches and neurological difficulties as nothing more than “aches and pains of daily living”. ILADS CPG concluded

that persistent Lyme disease symptoms (PLDS) can be severe and chronic and recommend treatment strategies proven to be effective.

Neither the IDSA nor the CDC disclose the existence of the ILADS treatment guidelines, leaving many physicians and patients to mistakenly believe there is only one set of treatment guidelines for Lyme disease.

“Lyme patients deserve the same courtesy as other patients,” added Cameron. “They have the right to make informed decisions about their own medical care after being offered a choice of clinically proven treatment options.”

*pha*

### About ILADS

About ILADS ILADS [www.ilads.org](http://www.ilads.org) is a nonprofit, international, multidisciplinary medical society, dedicated to the diagnosis and appropriate treatment of Lyme and its associated diseases. ILADS promotes understanding of tick-borne diseases through research and education and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases.

Media contact: Pam Kahl  
[pam.kahl@verbal800.com](mailto:pam.kahl@verbal800.com)  
503.284.1534

## Water... How much is enough?



by *Barbara Fritts*

C.U.D. is chronic, unintended dehydration. Most individuals function in a chronically dehydrated state and are unaware of the importance of proper hydration. Approximately 60% of the human body is comprised of water. Water is critical for the regulation of body temperature, blood pressure, heart function, joint lubrication and memory. Water is also essential for nutrient delivery and metabolic waste elimination from the body. In a state of dehydration, the kidneys turn to the liver for backup assistance, overburdening the liver's detoxification

capabilities and diminishing the liver's ability to convert stored fat into usable energy. The resulting reduced blood volume seen from dehydration can further cripple the body's ability to rid itself of noxious chemicals and to incorporate vital nutrients.

Some of the signs of mild dehydration can include: decreased coordination, fatigue, headache, low urine output, dry skin and mucous membranes, asthma and allergies. Thirst is not an adequate indication of when to replace fluids because the body is generally already in a state of dehydration when thirst is signaled. Often the feeling of hunger can actually be an indicator of the need for hydration. Interestingly, one of the functions of histamine in the body is to regulate the body's thirst mechanism and to conserve and regulate the body's water reserves. Dehydration thus can lead to increased levels of histamine throughout the body which in turn can exacerbate allergies and heighten environmental sensitivities.

The average person loses about 3 to 4 liters of fluid a day through sweat, urine, bowel movements and exhaled

respiration. Just breathing alone can be responsible for 1 to 2 liters of daily fluid loss. Exercise, excessive sweating, diarrhea, higher temperatures and altitudes can all contribute to an even greater daily fluid loss. Urine color can be an indication of dehydration and used to monitor short-term hydration levels. A state of dehydration will yield more concentrated urine having a dark yellow or even orange appearance. Proper hydration should render the urine a very light yellow or clear color. So how much water is generally regarded as enough? The most common formula for minimum daily fluid replacement is to divide one's weight in pounds by 2. This number will represent the daily minimum water intake amount in ounces (1 ounce = 0.029 liters). For example, a



person weighing 200 lbs. (to convert from metric, 1 kilogram = 2.20 lbs.) would divide their weight by 2 and thus their minimal daily water requirement would be 100 ounces (or 2.9 liters). Food may contribute to some basic fluid replacement but it is generally not enough to offset one's water needs based upon this formula.

Water is best consumed evenly throughout the day, keeping in mind not to drink fluids during meal time as liquids can dilute digestive secretions. Caffeinated drinks can actually further dehydration due

to caffeine's diuretic properties' so these drinks should be avoided or at least not counted toward daily water requirements. Also, carbonated water can leach calcium out of the body and may affect the body's delicate electrolyte balance; therefore, carbonated water should be minimally consumed.

When it comes to warding off the detrimental effects of dehydration and supporting the body's many water-dependant functions, there really is no healthier choice than adequate consumption of pure, filtered glass-bottled water. *pha*

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- \* Liver detoxification
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Page 7



MEDICAL PERSPECTIVES

Best Documentary: Infectious Disease Category  
*Under Our Skin* Wins Prestigious FREDDIE Award  
"Oscars" of Healthcare Films

(Sausalito, CA)- Under Our Skin, a documentary about the debilitating and often heart-breaking effects of Lyme disease, has just won a prestigious FREDDIE Award. The honor names the documentary Best Film about Infectious Diseases. A production of Open Eye Pictures of Sausalito, CA and filmmaker Andy Abrahams Wilson, Under Our Skin inves-

Lyme disease is among the most misunderstood and controversial illnesses in recent medical history.

tigates the human, medical and political dimensions of Lyme disease. The film casts one of the first media spotlights on the emerging epidemic that is destroying countless lives. Lyme disease is among the most misunderstood and controversial illnesses in recent medical history. The FREDDIES, sometimes referred to as the "Oscars

of Healthcare Films," are the preeminent media awards in the international health and medical fields. Each year, the competition attracts hundreds of submissions from around the world. Filmmakers and producers compete in 36 categories for the FREDDIE, the bronze statuette named in honor of the competition's founder, Dr. Fred Gottlieb. Judging is conducted by world-renowned medical and production professionals from across the United States. "We're honored to be recognized by the FREDDIE awards," says filmmaker Andy Abrahams Wilson. "This honor allows us allows us to again focus needed attention on the hundreds of people who shared their difficult stories of Lyme disease-as well as the millions more who are fighting for treatment, or sadly, have lost loved ones. The FREDDIE award helps us honor their courageous battles." Prior to the FREDDIE, Under Our Skin was an Audience Choice Award finalist at the Tribeca Film Festival, whre it had its world premiere. In addition, the film has received major news coverage from ABC's Good Morning America, The Washington Post, and Sirius XM radio's Oprah and Friends Channel with Dr.

"Not since Michael Moore has a documentary caused such a stir across America."  
  
-Fox News

Oz, among many others. Critics have called it:  
  
"Well-researched...suspenseful...artfully shot."  
-Variety  
  
"Emotionally charged!"  
-ABC News  
  
"Not since Michael Moore has a documentary caused such a stir across America."  
-Fox News  
  
The FREDDIES were officially awarded at a black-tie awards ceremony November 14, 2008 at the Crystal Tea Room in Philadelphia, PA. *pha*

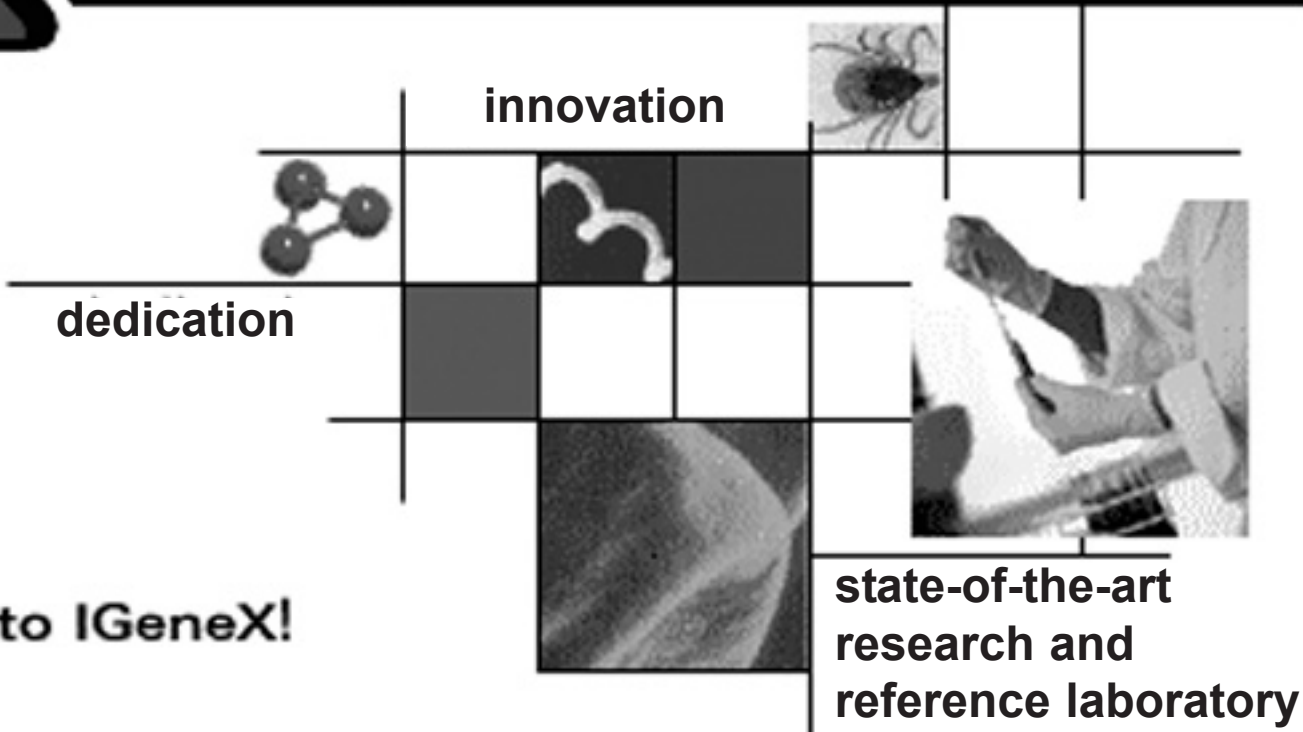


Open Eye Pictures filmmaker Andy Abrahams Wilson

"Well- researched... suspenseful...artfully shot."  
  
-Variety



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Kathleen

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214-749-2845

**Houston**  
Contact: Teresa Lucher  
[lucher@sbcglobal.net](mailto:lucher@sbcglobal.net)

**League City/ ClearLake & NASA Area**  
Sandra Mannelli  
[smannelli@comcast.net](mailto:smannelli@comcast.net)

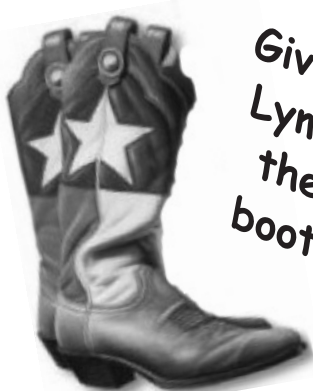
**Washington State**  
Alexis Benkowski  
WA-Lyme-owner@yahoogroups.com  
**WI / IL / MN Regional areas**  
Contact PJ Langhoff  
(920) 349-3855  
[www.Sewill.org](http://www.Sewill.org)  
[www.LymeLeague.com](http://www.LymeLeague.com) (Intl)

**Western Wisconsin Lyme Action Group**  
Marina Andrews  
715-857-5953



**Military Lyme Disease Support**  
Military Lyme Support is an online source of information and emotional support. This site is for Military Members, Veterans, and their family members who suffer from Lyme and other vector-borne diseases. Members are stationed in the United States and abroad.  
<http://health.groups.yahoo.com/group/MilitaryLyme/>

**Texas Lyme Disease Association**



Giving Lyme the boot!

[www.txlda.org](http://www.txlda.org)

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[donations@txlda.org](mailto:donations@txlda.org)

## “Vaccine Injury” ...cont’d from pg 2

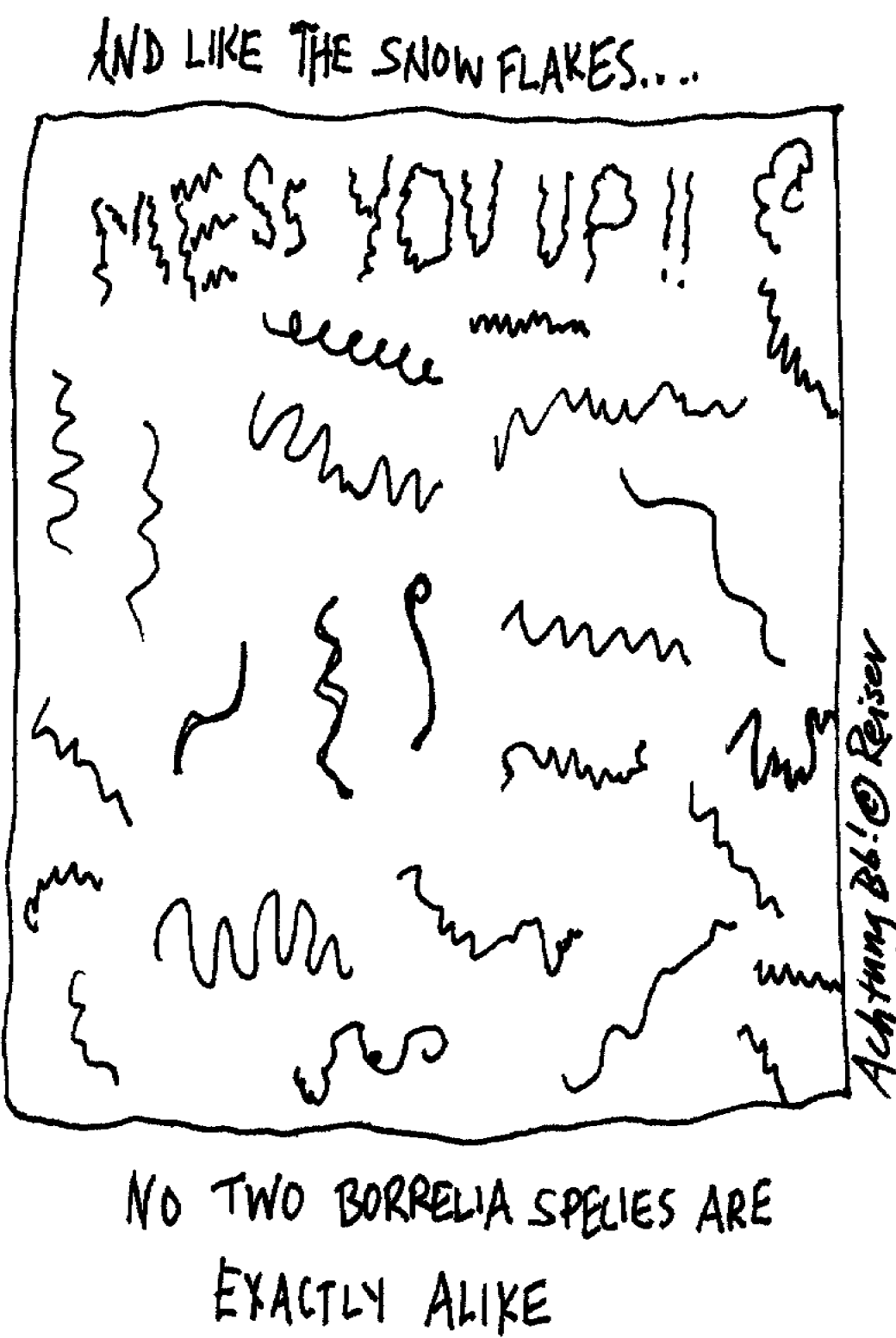
immunity from liability to an entire industry and he concluded that "in the absence of any clear and manifest congressional purpose to achieve that result, we must reject such a far-reaching interpretation." During the ACCV meeting, longtime plaintiff's attorney Sherry Drew gave a moving description of the suffering that families with vaccine-injured children endure and, during public comment at the end of the meeting, Jim Moody, of SafeMinds, and Vicky Debold, RN, PhD joined me in urging the Committee to recommend to the new Secretary of DHHS that more vaccine-injured children be compensated. This was echoed by outgoing parent ACCV member Tawny Buck, of Alaska, who has a DPT vaccine-injured daughter and new ACCV parent member Sarah Hoiberg, of Florida, who has a five-year old DTaP vaccine-injured daughter. In the 1986 Vaccine Injury Act, the Institute of Medicine was directed to review the medical literature for scientific evidence that vaccines can cause injury and death, which resulted in landmark reports to Congress in 1991 and 1994 providing that evidence. IOM announced at the ACCV meeting that it has recently been contracted by the Health Resources & Services Administration (HRSA) to assemble a Committee of scientific experts to review the medical literature for evidence regarding the biological mechanisms for injury and death in association with varicella zoster (chicken pox), hepatitis B, meningococcal and HPV vaccine. There will be several public workshops during the Committee's two- year study.

NVIC has been calling for basic scientific research into the biological mechanisms of vaccine injury and death for more than two decades. Without understanding how and why vaccines can cause brain and immune system dysfunction, there will be no way to develop pathological profiles to help scientifically confirm whether or not an individual has been injured or died from vaccination. The truth about vaccine risks lies in the science, properly designed and conducted. The upcoming IOM review may be hampered by a lack of biological mechanism studies published in the medical literature but the review is also an opportunity to point the way to fill in those gaps in knowledge and the need for additional research that could become part of a national vaccine safety research agenda. In the absence of scientific certainty, all children who regress into poor health after vaccination should be given a fair hearing in the federal vaccine injury compensation program and generously compensated when no other plausible cause can be found for what happened to them after vaccination. Congress intended the vaccine injury compensation program to be non-adversarial, fair, generous and humane. If it cannot function the way it was intended to function, then parents have every right to call for its repeal and a return to unrestricted lawsuits.

*pha*

Barbara Loe Fisher is the mother of three children, a writer and speaker on vaccination and informed consent issues.  
[www.NVIC.org](http://www.NVIC.org)

## Ticktoons



by Terri Reiser



# ILADS Announces Physician Training Program Clinical Expertise Key to Preventing Chronic Lyme Disease

Willy Burgdorfer keynote Speaker at Annual Conference

by [www.ilads.org](http://www.ilads.org)

Bethesda, MD— The International Lyme and Associated Diseases Society [www.ilads.org](http://www.ilads.org) today officially launched a physicians training program with the goal of decreasing incidence of chronic Lyme disease. The training program intends to train more than one hundred physicians over the next five years. The program has been underwritten by a grant from New-York-based *Turn the Corner Foundation*, an organization dedicated to the support of research, education, awareness and innovative treatments for Lyme disease and other tick-borne diseases.

“With more than an estimated 200,000 of cases annually, Lyme disease has become the leading epidemic of our time,” said Dr. Daniel Cameron, ILADS board president and internal medicine physician. “We need more physician-scientists who will be the future leaders in the treatment of Lyme and associated diseases.”

Increasing the number of physicians educated on the diagnosis and treatment of Lyme disease is a key goal in the fight against chronic Lyme

disease because advanced cases of Lyme are often the result of misdiagnosis or under treatment soon after a tick bite. Recently discredited treatment guidelines authored by the Infectious Disease Society of America (IDSA) reflect a narrow view of Lyme disease, making it difficult for physicians not well versed on the complexities of the disease to recognize symptoms and provide adequate treatment. There are no accurate diagnostic medical tests for Lyme disease.

The ILADS/TTC Physician Training Program represents the second phase of ILADS campaign to prevent chronic Lyme disease. The campaign, launched this summer with the release of Top Ten Tips for Preventing Chronic Lyme Disease, intends to raise awareness of the risks associated with the disease, provide prevention guidance to consumers and training for medical personnel.

## Evidence-based Medical Training

ILADS Physicians Training Program is designed to enhance clinical expertise for physicians with established



Dr. Willy Burgdorfer

“With more than an estimated 200,000 of cases annually, Lyme disease has become the leading epidemic of our time,” said Dr. Daniel Cameron, ILADS board president and internal physician.



medical practices. Curriculum is based on ILADS’ evidence-based treatment guidelines and focuses on the importance of hands-on experience complemented by thorough review of quality, peer-reviewed literature. During the one-two week program, participants partner with a designated ILADS Lyme literate physician and participate in the diagnosis and care of a variety of challenging early and chronic cases.

A pilot version of the program was launched in 2004. To-date, approximately 100 physicians representing a variety of geographies in the

United States have successfully completed the program.

“Effective treatment of Lyme disease requires a comprehensive approach to patient health care,” said Maureen McShane M.D, a family practitioner in Chazy, New York.

“ILADS’ physician training program was invaluable for teaching me how to better assess, diagnose and treat Lyme disease and possible co-infections.”

Applications for the training program can be obtained via email by writing to [lymedocs@aol.com](mailto:lymedocs@aol.com).

*pha*

## THE HIDDEN EPIDEMIC

that may be the cause of your pain  
visit our new website at:

[www.truthaboutlymedisease.com](http://www.truthaboutlymedisease.com)

Lyme Patient Stories  
Resource Links  
LD Support Forums

Lyme Awareness Store  
Acute and Chronic Patients Welcome  
Frequently Asked Questions

*New Teen Only Lyme Disease Forum forming!*

# Discover The Top 10 Lyme Disease Treatments

[www.Lyme-Disease-Treatment.com](http://www.Lyme-Disease-Treatment.com)



# The Pillaging Of Personalities: Our Lost Kids Are Being Hijacked By Spirochetes



by Virginia T. Sherr, MD

Opening the door of my office one day in May 2001, I stepped back in surprise. The teenager standing there wore a brilliant orange, neck-to-foot jumpsuit. There were shackles with chains between her wrists and she was hobbled by more chains between her ankles. Surrounding her were two rather determined-looking women, looking at me doubtfully. I had known that 17-year-old Vicki was coming from a juvenile detention unit, but I hadn't expected matrons, manacles and chains.

Vicki was brought to see me for a psychiatric opinion as to possible causes of behavior that led to her arrest and of her episodic rages. Apparently, in the prison, she was noted for being pleasant and compliant one moment, but suddenly, especially perhaps when there was a clang or scraping noise, flying into bizarre rages, wherein she had to be physically subdued and taken back to her cell by force. The matrons were decisive but generally friendly to her, she said.

Vicki's history, from her mother and herself, was of great interest. At age 7, she had a number of bull's eye rashes that were misdiagnosed as "ringworm." She suddenly became drastically ill and fell comatose. "Paralyzed all over," she was hospitalized. The specialist astutely diagnosed her as having Lyme encephalitis. Unfortunately, this serious condition was treated with only a 10-day course of IV antibiotics. She awoke from the coma looking good as new, and went home to a relieved family. Vicki, herself, could only recall "having trouble walking while in the hospital." Her mother reminisced that Vicki seemed different somehow after that, although she had never thought of a connection between these things before. Certainly, the child had undergone a personality change. Vicki had been agreeable as a young girl, but she gradually became antagonistic and had a loss of interest in grade school subjects. By age 11 she was downright oppositional. She used increasingly poor judgement and had inadequate control over her emotions. Schools classified her

as "Emotionally detached/Learning disabled" At about this time, Vicki's parents divorced, and her mother assumed that the coincidental turmoil accounted for her daughter's escalating personality change and worsening school performance. Vicki's mother said, "The change in her personality was such that I thought of finding an exorcist." Then came Vicki's defiant, delinquent behavior and brushes with the law. She pushed that aside entirely with the notion that her trouble only related to her friends' bad influence on her and their setting her up to take their raps.

Vicki's antibody blood tests came back with 5 positive Western Blot bands diagnostic for chronic Lyme disease. We were able to enlist the help of other skilled Lyme literate professionals to evaluate her further. They prescribed doxycycline and gabapentin for her persistent Lyme disease and its behavioral and cognitive consequences. At her court hearing in December 2001, their written testimony was offered regarding facts of her general and cerebral spirochete bacterial infection. A successful plea was entered on behalf of her release on electronic probation from what amounted to jail.

No one noticed much change in Vicki when she was she was noted for being pleasant and compliant one moment, but suddenly... when there was a clang or scraping noise, flying into bizarre rages, wherein she had to be physically subdued and taken back to her cell by force.

on the doxycycline, she and her mother said. However, upon my phone follow-up questioning in January 2002, Vicki described herself as having a "different state of mind - I'm calmer than I used to be. I can handle myself. I am not so tired all the time, and I am happier." Taking modafinil and gabapentin as prescribed, she also appeared to be more and more psychologically stable. In addition, she is not as physically symptomatic as she was before she took the recent oral doxycycline. The chronic

Lyme disease symptoms that, while she was in jail, felt to her just like her own personal peculiarities - chills, sweats, fatigue, multiple joint pains, headaches, rashes, difficulty thinking and concentrating, and trouble reading - all began to fade. Due to her mother's wise persistence, Vicki is undergoing medical evaluation for further antibiotic treatment. However, it is hard for Vicki to conceptualize that a brain infection might have been behind her serious troubles with judgement, Chad had totaled several cars when he came of age to drive. His anxious parents sent him to private military and juvenile training centers that he now thinks were of little help.

I first learned of Chad's situation when his mother asked if I would agree to see him. He had spent some time in jail with 5 charges pending against him, was due to see the judge in the morning, and she hoped it would help if a future psychiatric evaluation could be arranged. Apparently, a wary judge reluctantly approved Chad's transfer to house arrest.

At first it was touch and go at home - Chad's rages continued - in part because he still felt driven and restless. He craved release from house confinement. During the day, he continuously paced and at night he had dreams of alcohol and drugs - he was desperate for anything that would provide surcease from his near-explosive agitation and wished to be rid of his ankle monitor. Only the fear of the greater confinement of a return to jail helped to keep him in the house and then barely so. He managed my prescriptions irresponsibly (At that time, his medications included risperidone, benztropine mesylate and an occasional alprazolam when he experienced panic attacks), necessitating that his mother administer even the mildest

the law - "I was just immature." she says, "Now I want to get an education - I want my life back."

Vicki is at home under house arrest now, wearing an electronic "bracelet" (monitor). She hasn't experienced life in the crucible of the outside world since she was treated with the recent antibiotics. The greatest challenge she faces is the general one facing Chad, an 18-year-old youth whom she has never met, but whose saga is so similar to hers that they seemed to have been cloned.

Chad was described by his mother as being "the most agreeable child I have ever known. Good humored, intelligent, he was a big favorite of all who knew him as a little boy." Bitten by a deer tick at age 13 with resultant bull's eye rash, he was treated, as per medical convention then, for 30 days of only twice daily oral doxycycline. He too, underwent a personality change and gradually became defiant, delinquent and seriously depressed. He demonstrated extremely poor judgement. His mother often said that due to the extreme change in his personality, it seemed as if he were "possessed." Chad turned to drugs and alcohol in part for pleasure, but also because they quelled a strange inner restlessness which kept him urgent - pacing and racing. Because of his poor

judgement, Chad had totaled several cars when he came of age to drive. His anxious parents sent him to private military and juvenile training centers that he now thinks were of little help.

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medications. Testing was positive both for the presence of DNA of the causative spirochetes and the presence of his antibodies to them. There were 6 positive bands on his Western Blot blood test for chronic Lyme disease. His SPECT scan showed diffuse hypoperfusion (lowered blood supply compatible with Lyme disease) of his brain.

Currently, Chad is more responsible with his medications. They now consist in part of gabapentin, mirtazapine and

olanzapine. The risperidone is being phased out. He says that he could feel the clarithromycin antibiotic working to help him the day he started it. He is calmer now, but like Vicki, he is not yet ready to be fully tested in our complex world. And, like Vicki, Chad is reluctant to believe that his floridly positive tests for chronic Lyme disease and his clinical diagnosis of neuroborreliosis could have anything to do with his behavior. Teens are no exception to the fact that people like to believe they are fully in charge of themselves, even if they are making major mistakes. Seeming to cop out with the excuse of having a chronic brain infection appeared totally unacceptable to him.

Both of these young people have lost any idea of what they really are like, what they are capable of, or who they could be. They do not remember and have lost track of the person they started out to be. Their childhoods were distorted by ticks laden with spirochetes, long-lasting agents that are toxic to personality maturation. Each had dramatic personality changes over which they had no control and which were explained away as coincidental to some current event unrelated to the tick bite. Each mother had the feeling that her child must have been "possessed," although they did not really believe in that possibility. In truth, these two young people were possessed-they were taken over by an unrecognized nervous system infection that pillaged their normal development.

The challenge now for each young person is to undertake the missed steps of lost maturation, recover a healthy sense of self and to use it to adapt to the real adult world in ways that work for them and for society. This may prove to be a Herculean task. It is an ongoing experiment as to whether

Vicki and Chad can surmount the loss of 5-10 formative years and, in Chad's case, the coincident abuse of the street drugs and alcohol that falsely promised relief from the symptoms of tick-borne disease.

Gradually, these two young people are beginning to understand the importance of dealing with the minute terrorists that hijacked their childhoods. Their own government once destroyed perpetrators of piracy on the high seas and lately it has not been reluctant to seek out and destroy human terrorists. One wonders when the same aggressive attention will be given by our government to tick and spirochetal plunderers of this generation of America's pirated children. Make no mistake-it then could be possible that the need for aggressive attention to the lost children themselves would become unnecessary.

pha



she was noted for being pleasant and compliant one moment, but suddenly... when there was a clang or scraping noise, flying into bizarre rages, wherein she had to be physically subdued and taken back to her cell by force.

The challenge now for each young person is to undertake the missed steps of lost maturation, recover a healthy sense of self and to use it to adapt to the real adult world in ways that work for them and for society. This may prove to be a Herculean task.



# “The Ruins” ...cont’d from pg 3

both good and bad-there is a far deeper story than what you see by simply meeting me. My story tells the story of many others...multitudes of others! My story also shows the faithfulness of God, still sovereign and moving in a modern generation. My story tells of a tenacious doctor willing to put his patients above politics and practice the oath he took when he became a physician-to first do no harm-even when it put him squarely in the middle of a medical controversy. He chose the patient’s health over his personal concern over the controversy of his decisions. Because of his medical choices I am still walking. I thank him and God for that. Because of his bold medical decisions and persistence to go the distance, I am no longer bed-ridden, but will be attending graduate school in 8 weeks. I can thank God and Dr. Forester for that. My story encompasses their stories. I find there is much to reflect on.

This is the time of year where reflecting on life is very important to me. There is something about the holiday seasons that cause a lot of reflection and introspection. That can be both good and bad. The contents of this particular issue of the PHA reflect that perfectly. We see great strides with ILADS advancing their physicians training program at the same time we mourn the tragic loss of a tremendous Lyme patient advocate, Leslie Wermers. I think of Leslie's sister, Tracie Schissle, and how

the holidays must be bearing down on her -- and in my heart I know Leslie's desire for Tracie is to rise like a phoenix out of the ashes and continue down the path of advocacy the

I remember closing out the 2007 year this time last year and my daughter surviving her coma that was brought on by a Lyme-induced case of Meningitis. This year of 2008

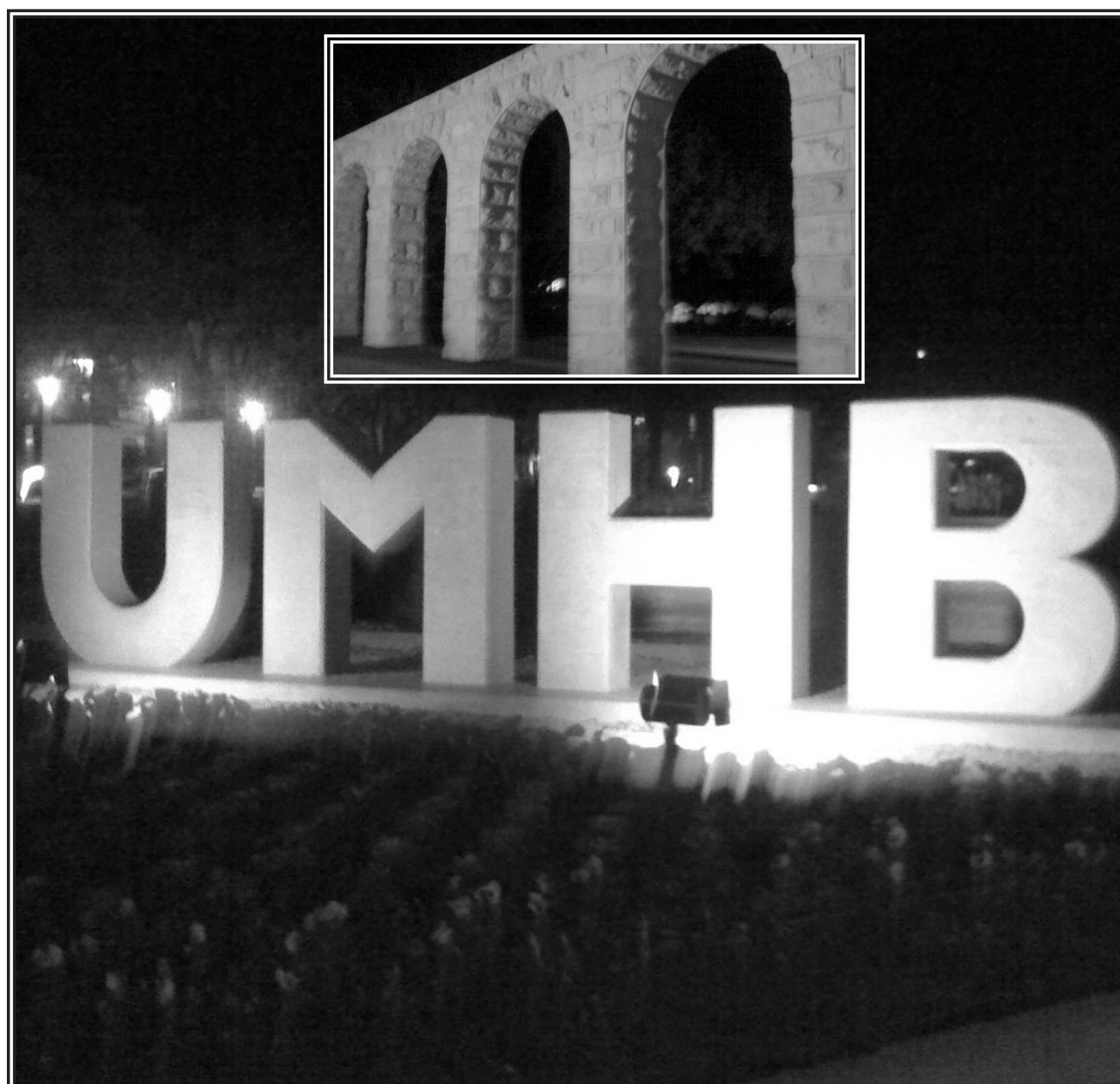
plating launching a Christian newspaper. In November of 2008 I did it! By the end of January 2009 we should have it out in hard copy! Last year I was accepted to graduate

versy that surrounds the IDSA vs. ILADS treatment protocols, and I cannot imagine where I would be right now if I had just accepted the measly 6 weeks of antibiotics and learned to deal with what the IDSA called "the aches and pains of daily living." I personally think not being able to walk and not having full use of my legs is a tad bit more than the average "aches and pains of daily living"... but I digress!

I thank God for Dr. Jonathan Forester in Pineville, Louisiana who has been able to medically treat my/our Lyme disease, and pray with me and my family. He has been a very integral part of giving us back our lives and health. I can without a doubt say, that had we not found him when we did, I would not be alive today. He literally saved my life, and that of my family. I owe a debt of gratitude to Dr. Forester that I can never repay.

My hope for you, the readers and friends of the PHA, is that as you look at the ruins of your own life, you will find the strength, like the phoenix, to rise from the ashes.

It is my prayer for you all that you will seek God as priceless gift this holiday season. He is the only one who can trade your ashes for beauty, your sorrow for joy...He can turn our mourning into dancing again. May God make the ruins of your life into a beautiful memorial that will draw people to you that you may testify to them, "look what my God has done for me!" *pha*



*A trip back to my college helped me remember a simple truth:  
God is still in the business of rebuilding strength out of the broken rubble of ruins.*

two close-knit sisters had put their heart and soul into for hope of a brighter tomorrow for Lyme disease patients everywhere.

I reflect on my own life.

had its own share of trials and tribulations, but I have seen the best progress of my Lyme treatment this year and I am simply amazed.

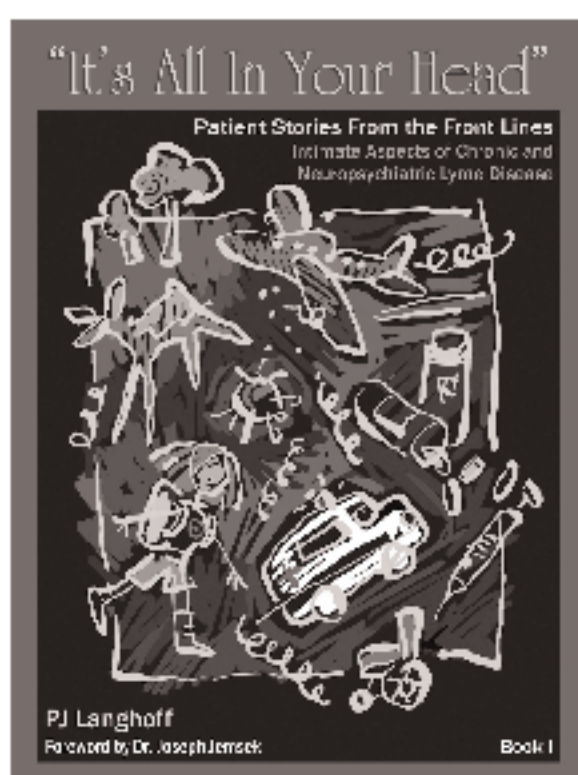
Last year I was contem-

school, but was unable to attend. This year my classes start in early January! I am just weeks away from realizing that dream!

I think of all the contro-

## Now Available: A New Book Series About Lyme Disease From PJ Langhoff

### “It’s All In Your Head”

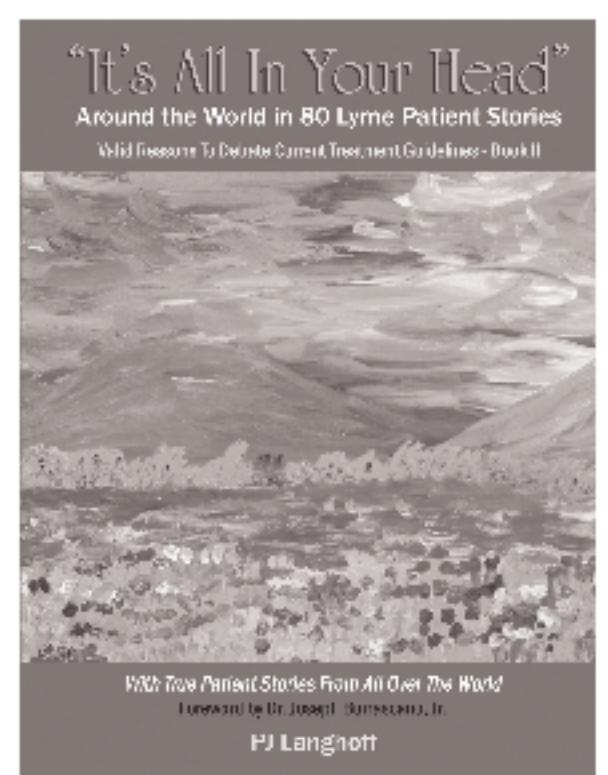


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and True Patient Stories  
Behind an Epidemic**



#### **"It's All In Your Head," Patient Stories from the Front Lines: Intimate Aspects of Chronic and Neuropsychiatric Lyme Disease**

Book 1 in the 3-book series. A personal and revealing look at individuals suffering from "chronic" Lyme disease, and what it's like living with neurological and psychological effects of an illness poorly understood and barely acknowledged in today's medical community. Includes a half dozen personal stories as told by patients (including the author's story), a history of Lyme Disease, co-infections, Herxheimers, Munchausen's, Faulty Diagnostic Testing, the politics, and more. Cover art by artist/Canadian Lyme patient, Valerie White. Foreword by renowned Lyme physician Dr. Joseph Jemsek.

#### **"It's All In Your Head," Around the World in 80 Lyme Patient Stories: Valid Reasons to Debate Current Treatment Guidelines**

Book 2 in the series. Lyme disease is NOT just a rash and knee illness! Learn what it is in this startling collection of 80 powerful personal stories from Lyme patients around the world. Stories told by patients in their own words, revealing the true nature of Lyme, that in its chronic, untreated form, debilitates and disables thousands. We reveal that Lyme may be transmitted sexually, in utero, via breastfeeding, and via blood and organ donations. Learn how patients coped with various treatments, co-infections, and the emotional and socio-political issues. Stories from 23 of the United States, 5 Canadian provinces/territories and 11 countries abroad, from all walks of life. A true population sampling of an epidemic illness. Includes brief commentary and history. Cover art by young artist/Lyme patient, Stephen Mills. Foreword by renowned physician/researcher Dr. Joseph Burrascano, Jr.

#### **The Baker's Dozen and the Lunatic Fringe, How "Junk Science" Shifted the Lyme Disease Paradigm COMING SOON!**

Third in the series. A revealing study on the politics of Lyme, the history, research, diagnostics, vaccines, patents and grants of top academic researchers and institutions. Learn more about Lyme, see the controversy, learn why patients can't get their illness acknowledged, and gain a greater understanding from the patient perspective. Includes brief overview of biowarfare technology as it relates to Lyme disease.



Wasted Days

by Tracy Will

Day after day slides by  
Piled up like bones in a  
Graveyard  
Higher and higher,  
Never getting buried.

Sticky, slimy,  
Sweaty days  
Blurry, foggy,  
Dizzy days  
They just slip by.

I lie here  
Like I'm watching a  
movie of someone  
Else's life.  
When do I get  
To wake up?

Summer, Fall,  
Winter, Spring  
Again, again,  
and yet again

Now the days have  
twisted somehow  
Into years

Once in a while  
A day becomes crisp  
I can breathe the air  
and hear the sounds  
But mostly, I lie here.

Day after day slips by  
Until a real tangible  
chunk of my life  
has escaped me.

I cannot reclaim it  
I cannot get it back.

Most insidious of all  
Are the years of life  
stolen from my child,  
who has no mother.

No one to play with  
him, no one to care for  
Him, no one to help  
with homework.

His life is slipping by  
Day after day  
Spent on a computer  
When he should be  
outside laughing  
and playing.

Night after night,  
watching TV  
Rather than reading  
or playing a game

Year after year,  
grades sliding down,  
homework not done  
No parent to guide him

Week after week,  
cereal for dinner

No one able  
to cook for him

Steal my life,  
steal my joy  
Leave me a shell  
of my self

But you have also stolen  
someone's childhood  
And I can't fix it...

I try, I try,  
for years I've tried...

Pills and supplements  
Shots and IVs  
Doctor after doctor  
Still I try...  
Still I lie here...  
A shell of a person...  
A shadow of a mom...  
A hollow life.

“Flu Vaccine” ...cont’d from pg 6

❖ preservatives such as formaldehyde, a known carcinogen; chemical disinfectants; Thimerosal, a mercury derivative thought to affect the central nervous system; aluminum (added to promote antibody response); ethylene glycol (anti-freeze)

The internet is filled with anecdotal material about serious complications due to flu vaccines. Are the neurological symptoms, mini-strokes, skin rashes, etc really due to the flu vaccines? There is no 'proof' just as there is no 'proof' for the damage done to some children as a result of childhood immunizations. The connections are there in the mind of the one who suffers and their family. Perhaps it was the flu vaccine or perhaps an unknown compromise that already existed which was exacerbated by the flu vaccine. No one knows for sure.

In the end, the decision is yours. If you choose to vaccinate, for certain, make sure you are in good health when you get the shot. You want

your immune system in its best possible condition to take on what the injection will introduce into your body. If you are not feeling well on the day you are scheduled for the vaccine, consider re-scheduling your appointment. Discuss your options with your physician and take charge of your wellness because you educated yourself not because 'they said'.

How to Protect Yourself

The price of independent thinking is the responsibility to protect yourself and your family.

Homeopathic Protection for Vaccinations

To help offset some of the possible negative side effects on the immune system, you can give homeopathic Thuja 30C (30C is the potency) (One dose = 2 pellets dissolved in mouth or dissolved in a little water and then put in mouth. Must be taken 15 minutes away from food.)

Five doses are given:

❖One dose the evening before the shot

❖One dose on the morning of the shot

❖One dose following the shot in the afternoon or evening of the same day

❖One dose on the morning after the day of the shot

❖And one more dose that evening

Thuja is a homeopathic remedy usually found in health food stores. Otherwise it can be ordered from 1 800 BLU TUBE.

I've never taken a flu vaccine because:

(a) it's not guaranteed to prevent me from getting the flu (because the flu vaccine is made long before the actual flu strain of the season is even known) and

(b) the flu vaccine is prepared in a base of sub-

stances I'd rather not take into my body and have challenge my immune system.

So what do I do? I prepare for the season with what I call my Cold and Flu Arsenal. It will help to keep your immune system engaged preventatively and give you tools to utilize at the first sign that 'something's coming.'

My 'cold and flu arsenal' is available in my 28 page booklet, "How Do I Get My Family Through the Winter? Herbs, Recipes and Guidance for Winter Wellness." The information helps you take charge of your family's wellness with safe, simple-to-follow recipes and techniques and easily-obtained formulas. It's a wonderful reference, making you feel empowered by knowing what to do to protect yourself and your family.

To order, contact Andrea at AndreaCandee.com or 877 856 7680. The booklet is \$7 + \$1 s/h.

**Andrea Candee**, MH, MSC is a master herbalist and instructor for the NY Botanical Garden. Holistic media expert and speaker, she lectures about taking charge of wellness naturally. Her book, Gentle Healing for Baby and Child (Simon & Schuster), was awarded The Seal of Approval by The National Parenting Center. Andrea is known nationally for her successful approach to reversing chronic Lyme Disease, and gives workshops upon request.

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Whitaker, Julian MD, Health & Healing

Wright, Jonathan MD, Nutrition & Healing

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“Women’s Retreat” ...cont’d from pg 4

many women with illness back from attending. Let them know costs may be covered.

Assign a person in charge of overseeing the necessities of those with chronic illness.

Choose your "healthiest" person with a chronic illness, or a cancer survivor, to communicate with those with illness and listen to their needs and concerns. The women who responded to the survey still do attend retreats and most say they approach the retreat planner ahead of time about their health issues. But for the dozens of others who would

like to attend, but assume you are unable to accommodate their needs, they never contact the church. Try to reach the women who assume they are unable to go by putting a special line on your promotional flyers that say, "Coping with chronic illness? Ask us about our special accommodations! We'd love to have you come!"

One of the most overlooked gifts in our church are those who live with chronic illness or pain. Despite their daily suffering, they have a great deal of wisdom and joy for the Lord.

pha

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while living  
with a chronic  
illness...

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# I Recommend Researched Nutritionals® for My Patients

...Joseph Burrascano, M.D.



Joseph Burrascano, MD

## The Mitochondrial Component

One of the most common complaints among our patients is lack of energy. I became intrigued with NT Factor Energy™ during a medical conference presentation which showed a 40% reduction in fatigue in eight weeks <sup>(1)</sup>. When I tested my patients on this product, they reported a noticeable improvement in energy. The product's success is due to its ability to deliver a stabilized and absorbable phospholipid complex to promote healthy mitochondrial membrane potential.



## The Immune Component

Most of our patients' immune systems are very weak. In order to provide the nutritional support for a healthy immune system, I recommend Transfer Factor Multi-Immune™. These folks have put a lot of thought into developing a product which promotes healthy natural killer cell function. The combination of transfer factor and the herbal and nutritional base make this an extremely effective product.



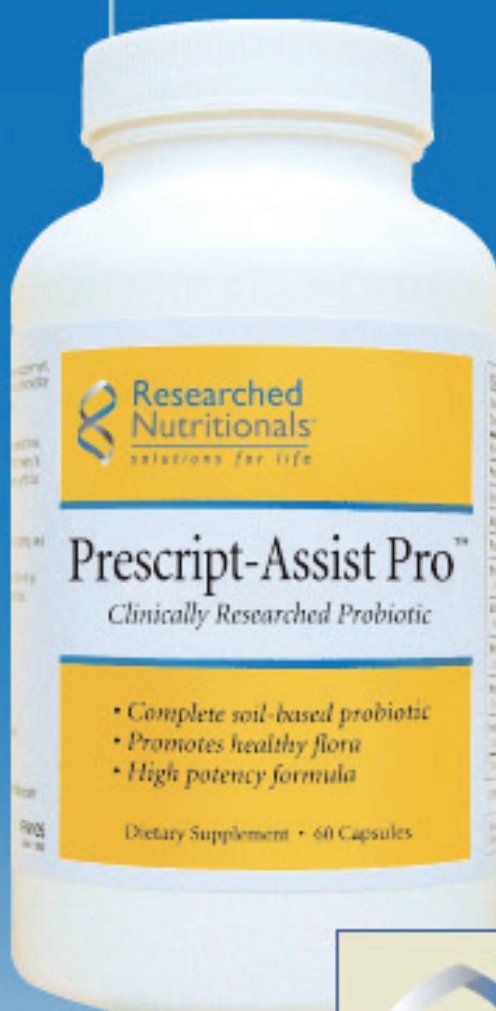
## Adrenal Component

I believe that we also need to address adrenal fatigue. Energy Multi-Plex™ includes fourteen researched nutrients to support adrenal health, including D-Ribose, Panax Ginseng, Acetyl-L-Carnitine, Alpha Lipoic Acid, Pyruvic Acid, 7 Keto DHEA, CoQ10, Methylcobalamin and L-Taurine. Patients like the convenience of this comprehensive formula versus taking three or four different products. Plus it saves them money.



## The Gut Component

Prescript-Assist Pro™ is clearly a step above what has been generally available, and I highly recommend it. If you do not have enough good gut flora, then you may not only develop GI upset and bad flora overgrowth, but you may also develop food allergies and other ugly stuff. There is nothing more important than a good probiotic. This product was developed to assist you if you are taking antibiotics – Prescript-Assist Pro™.



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Nutritionals®**  
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<sup>(1)</sup>Journal of the American Nutraceutical Association 2003; 6(1); 23-28. Available only through health care professionals.

\*These statements have not been evaluated by the FDA. These products are not intended to diagnose, treat, cure or prevent any disease.



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